

Statements from the President's Cancer Panel Meeting

Improving Cancer Care for All: Real People, Real Problems November 16-17, 2000

"It is time to stop talking" about disparities in access to cancer care and "start doing something" about them. Passionate testimony put human faces on issues related to health disparities as patients, survivors, family members, health officials, and health care providers from states and territories in the Southeast region of the United States addressed the President's Cancer Panel in Nashville, Tennessee, regarding barriers they face in both accessing and providing cancer care. Some barriers are inherent in the health care system itself. Although access to screening programs has improved largely as a result of Federal funding efforts, access to sustainable, community-based care has not. Underserved communities are "tired of being studied" under short-term grants, because needed services are discontinued after intervention studies are concluded. Dedicated but overwhelmed private health care providers cannot continue to absorb the costs of treatment for uninsured and underinsured individuals who are diagnosed through screening programs. "We need to be intellectually honest," according to one advocate, "about the impact of the health care system on access to care. It is disingenuous, within a payment-for-service system, to express surprise that some who cannot pay do not have equal access." Managed care organizations produce report cards on spending, but there are no report cards on health outcomes.

Other barriers stem from the financial impact of cancer on individuals and families. For example, physician recommendation is the primary factor that motivates people to seek screening; however, uninsured and low income individuals usually seek care only in times of crisis; it is not surprising that they are disproportionately represented among those whose cancers are diagnosed too late. Inadequate reimbursement for services at rural clinics often means that patients must travel to distant medical centers; some simply choose to forego treatment. Small things-such as the rising cost of gas or a lack of child care-become deciding factors in accessing care. Some patients risk losing their jobs due to inflexible limits on short-term disability coverage. Employment and insurance discrimination still exists for cancer-free survivors.

Geographic barriers to cancer care access include lack of transportation for residents of rural areas and lack of health care providers within rural communities. Isolation is a particular problem for residents of the U.S. Virgin Islands, for whom travel is especially costly and disruptive. Within rural areas, as well as in poor urban areas, disparities driven by poverty and illiteracy do not differ significantly among racial, ethnic, or regional populations, whether they are African Americans in western Tennessee, the Mississippi delta, and the "Black Belt" of Alabama or whites in Appalachia. Psychosocial barriers are no less real than financial and geographic barriers. For the poor and the underserved, fatalism is caused by a lifetime of experience. Distrust is entrenched among populations that have been poorly served.

However, patients who first react to a cancer diagnosis with fear or apathy are often motivated by meeting survivors and hearing their stories. Religious faith is a strong theme in the stories of many survivors and often provides the context within which survivors work to help others. Religious institutions are an important avenue through which education and prevention programs can gain access to underserved communities.

Lack of easily obtainable and easily understood information is a formidable barrier to access. Doctors should ensure that newly diagnosed patients have access to culturally appropriate medical information and guidance in finding financial and emotional support. In the Southeast, the access problems of Latin American and Asian immigrants are exacerbated by cultural factors, language barriers, and sometimes legal status. Cancer information dissemination cannot rely on generic messages; a multidisciplinary approach is needed to address the complexities of motivation and behavior change. Case managers or "navigators" can help patients understand the system and make connections with support groups. Nurses and social workers can play this role, but many advocates suggest using Community Health Advisors to help patients find information and services. Cross-cultural training for providers is also needed.

The President's Cancer Panel is an advisory group established by Congress to monitor the Nation's efforts to reduce the burden of cancer. The Panel reports directly to the President annually on delays or blockages in that effort. The Panel is currently holding a series of regional meetings to explore problems that prevent us from getting the best known cancer care to all people. Participants in the Nashville meeting included representatives from Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, Puerto Rico, South Carolina, Tennessee, and the U.S. Virgin Islands. For more information, visit the Panel's web site at <http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp.htm>, call 301-451-9399, or e-mail to pcp-r@mail.nih.gov.